

Understanding How Disability is Defined and Conceptualized in the Literature

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A goal of rehabilitation nursing is to advance the care of persons with chronic disabling conditions by minimizing disability. There are two distinct perspectives in the literature about how to conceptualize disability. Definitions and models of disability that inform rehabilitation nursing practice are based on a functionalist perspective of illness and locate disability as a problem of individual functioning. Alternatively, there are definitions and models that have evolved from the civil rights and social justice perspectives, and that locate the problem of disability within a disabling society. Recent attempts to integrate these two perspectives are based on earlier rehabilitation models and the functionalist assumptions remain. Rehabilitation nursing research and practice based on either of these two

perspectives is fragmented and incomplete. To know how to define and approach disability-related issues, it is important to understand how people living with disability perceive its influences on their lives.

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A primary goal of rehabilitation nursing research is to enhance the care of the person with disabilities (PWD) by minimizing the effects of disability. Rehabilitation nursing practice is based philosophically and theoretically on both the rehabilitation model of disability and the conceptual models and theories of nursing (Derstine & Hargrove, 2001; Secrest, 2000). While nursing theories and models for practice conceptualize how to provide care to PWDs, the rehabilitation model of disability provides the framework for conceptualizing disability. The rehabilitation model, and therefore rehabilitation nursing, is based on a functionalist perspective of illness and conceptualizes disability as a problem of individual functioning.

The social model, an alternative model of disability, is based on the civil rights and social justice perspectives. The social model conceptualizes disability as a problem of the social and physical environments constructed by society. Recognizing the discrepancies between the two perspectives and the resulting models, rehabilitation researchers and practitioners have developed new models that are designed to integrate the two perspectives (Brandt & Pope, 1997; Peters, 1996; World Health Organization, 2001). This article explores how disability is conceptualized from the rehabilitation, social, and integrated perspectives; highlights some of the differences; and discusses implications for rehabilitation nursing policy, practice, and research.

The rehabilitation perspective

The rehabilitation perspective evolved from the social institution of medical care and is rooted in Parsons' (1951) sociological paradigm of functionalism. In this paradigm, the social world "exists as a whole unit or system which is comprised of interrelated functioning parts" (Bowers, 1988, p. 33).

For the system to function effectively, all of the parts (in this case, human beings) must be able to fulfill their expected roles. That is, it is the responsibility of human beings to function in socially expected roles that promote optimal operation of the larger system. According to this paradigm, when individuals deviate from their expected roles, the larger system cannot operate properly. Therefore, to promote optimal function of society, social institutions have the power and authority to ensure that people are able to perform their socially defined roles (Parsons).

For example, in health care, professionals have the social power to control, modify, or eliminate the "deviant" behavior of illness (Weiss & Lonnquist, 1997). From this perspective, healthcare providers have a responsibility to cure "sick" people and return them to full function by eliminating their disease. Conversely, it is the responsibility of "sick" people to seek help from, and comply with, the instructions or "orders" of healthcare professionals (Edge & Groves, 1994; Roberts & Krouse, 1988). The tenets of this paradigm are pervasive and implicit, not only in rehabilitation definitions and models of disability (Myers, 1965; Nagi, 1965), but also in many of the nursing theories that guide rehabilitation nursing practice (Fawcett, 1993; Meleis, 1997).

In a functionalist paradigm, PWDs are "obligated to try to become rehabilitated if possible" (Myers, 1965, p. 38). One of the consequences of this paradigm is that as long as a person is not "fully functional," he or she is "exempted from [his or her] normal social responsibilities" (p. 38) and is expected to be dependent on others for care. Therefore, for PWDs who cannot regain full function, the assumptions inherent in this perspective place the PWD in a chronic role of dependency.

Past and present definitions and models of disability in the rehabilitation literature reflect these functionalist assumptions. Myers in 1965 (p. 35) described a person with a disability as "one who, because of his physical or mental handicap, cannot or is not permitted by community members to function in his social roles." A second definition, written 30 years later in a study commissioned by the Institute of Medicine, has the same focus on function and performance of expected roles as its predecessor:

Disability is defined as a limitation in performing certain roles and tasks that society expects an individual to perform. Disability is the expression of the gap between a person's capabilities and the demands of the environment—the interaction of a person's limitations with social and physical environmental factors. (Brandt & Pope, 1997, p. 25)

While this later definition includes a statement about the interaction of the person with the environment, its focus remains on a person's ability to function in socially expected roles, and it carries with it the assumptions of the previous definitions that were developed from a functionalist perspective.

The rehabilitation models of disability, on which rehabilitation nursing research and practice is based, were developed from this perspective and carry with them the same assumptions. The first draft of the rehabilitation model was developed by Nagi (1965) as an extension of the medical model.

The medical model is conceptualized as a linear model beginning with the etiology of the disease, followed by its pathology, and the resulting manifestations (Minaire, 1992). The medical model focuses on the disease process itself, with the goal of curing the disease and returning the patient to normal functioning. While the medical model was useful for research and practice in the diagnosis and initial treatment stages of a disease, rehabilitation professionals recognized that there were other factors to be considered when studying the effect of a chronic disease or disability on a person's longterm ability to function in society (Nagi, 1965).

Nagi (1965) adapted the medical model and developed a more comprehensive model of disability. Several other researchers have revised this framework in the past 35 years. In the late 1970s, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities, and Handicaps (WHO ICIDH) (WHO, 1980). While the WHO ICIDH model does not acknowledge the influence of the Nagi scheme, there are many similarities in these models. These two models are the most commonly referenced models in the rehabilitation literature and are the philosophical and theoretical frameworks of disability that guide rehabilitation nursing practice (Derstine & Hargrove, 2001; Secrest, 2000). While both the Nagi scheme and the WHO ICIDH provide a more comprehensive schema of disability than does the medical model, they are based in the functionalist paradigm and their central (and defining) construct is the disease or pathology and its resulting effect on functioning.

In the past 10 years, rehabilitation health services researchers

have revised the Nagi (1991) and ICIDH models. The revisions included the addition of societal limitations (Jette, 1994); environmental and individual factors, and risk factors (Verbrugge & Jette, 1994); and quality of life and health status (Ebrahim, 1995; Pope & Tarlov, 1991). Yet, even with these revisions, it is the rehabilitation model and all of its variations that locates disability in the person; its central focus is on the disease process and the patient's resulting functional limitations. This model is also known as the individual model of disability in some literature.

The social perspective

The second perspective has its roots in the historical and political tradition of the civil rights movement, social justice, and consumerism (DeJong, 1979; Hahn, 1993). This perspective began to emerge in the late 1960s, and was in partial response to the prevailing emphasis on functioning and the focus of the rehabilitation perspective that disability was a form of deviance to be eliminated or reversed (DeJong; Hahn). These sociopolitical movements evolved from the belief that certain groups or classes of individuals, such as PWDs, are oppressed by the more powerful classes in society—for instance, healthcare professionals. The main purpose of these movements was to make visible the imbalances in power and to secure the rights of the less powerful people in this society. The goal was to shift the emphasis and the burden of disability from the PWD to society.



The approach to ameliorating disability centers on changing social attitudes, institutions, and policies

This perspective presumes that people with disabilities are discriminated against, marginalized, and oppressed (Hahn, 1993). Resulting definitions and social models of disability focused on minimizing disability and improving quality of life by affording PWDs the same rights and opportunities afforded to other members of society. A major assumption of the social perspective is that PWDs should be independent and should have the same rights and responsibilities as people without disabilities. This is accomplished through empowerment, self-determination, and activism (DeJong, 1979).

This perspective defines disability as a product of the social and physical environment. Disability results from restrictions created and imposed by society, which, in turn, causes restricted opportunities for the PWD. The approach to ameliorating disability centers on changing social attitudes, institutions, and policies. This perspective is evident in the following definitions:

Disability is not a condition of the individual. The experiences of disabled people are of social restrictions in the world around them, not being a person with a 'disabling condition.' This is not to deny that individuals experience 'disability'; rather it is to assert that the individual's experience of 'disability' is created in interactions with a physical and social world. (Swain, Finkelstein, French, & Oliver, 1993, p. 2)

Disability Defined

Disability is manufactured by attitudinal and environmental barriers rather than functional limitations. (Finkelstein, 1993, p. 39)

The models coming from the social perspective "locate disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment" (Marks, 1997, p. 88). Disability is perceived as the result of the discrimination, prejudice, and stigmatization (Hahn, 1993), and forced dependence on relatives and healthcare and other professionals (DeJong, 1979).

The most widely referenced of the social models in the United States is the independent living (IL) model.

The most widely referenced of the social models in the United States is the independent living (IL) model. From its perspective, the rehabilitation process, because of its "dependency-inducing features" (DeJong, 1979, p. 443), is viewed as part of the problem of disability. The IL model identifies the problem of disability as "not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large" (DeJong). Advocates of this model propose that PWDs trade the dependent role of patient or client, for the independent role of consumer and activist (DeJong; DeJong & Brannon, 1998; Marks, 1997).

In the IL model, proposed solutions to the problem of disability include empowerment, self-determination, advocacy, consumer control, removal of environmental barriers, and political activism (DeJong, 1979; DeJong & Brannon, 1998). A primary tenet of the IL model is that PWDs have expertise about disability and that programs and services should be determined, designed, and directed by PWDs. For example, according to the model, personal care assistant services in particular should be individually controlled and directed by the PWD, rather than by formal systems of care. In other words, personal care workers should be recruited, hired, trained, managed, paid, disciplined, and fired (if necessary) by, and be accountable to, the PWD rather than to an organization. This model also advocates flexible policies and benefits systems whereby PWDs determine the best use of funds that have been allocated for their well-being (DeJong & Brannon).

Integrating the models

Recognizing that the rehabilitation and social models were oppositional in nature, but that there were strengths in each, several researchers in the past 5 years have attempted to integrate them by placing more emphasis on the interaction of the person with the environment (Brandt & Pope, 1997; Peters, 1996; WHO, 2001). However, these integrated models were derived primarily from the earlier rehabilitation models and the assumptions inherent in those earlier models still held. Most importantly, in the integrated models the health condition (i.e., the disease or disorder) and resulting functional limitations of the patient remain the central focus.

For example, the WHO International Classification of Functioning, Disability, and Health (ICF) (2001), which evolved from the International Classification of Diseases and the first WHO ICIDH model (described earlier), was designed to integrate the components of the medical and the social models of disability (Gray & Hendershot, 2000; WHO, 2001). According to its authors, this integrated model provides unifying dimensions and domains of health conditions for researchers and providers when classifying or mapping the impact of a disease or disorder on individual functioning (Gray & Hendershot; WHO).

While the goal of the ICF is to integrate the perspectives of the social and medical models, as in previous rehabilitation models, the defining construct is the health condition (i.e., the disease or disorder) and its resulting effect on individual function. Disabling barriers of society are considered as context; however, functionalist assumptions prevail in the ICF by continuing to direct our attention (as researchers and practitioners) to the health condition and its effect on a person's ability to function in social roles.

Discussion and implications

The conceptual models of disability found in the literature reflect two very different perspectives. The rehabilitation perspective locates physical disability within the person and presumes that he or she is dependent on society until he or she can function in socially expected roles. If this is not possible, then the person remains permanently in a dependent role.

This perspective tends to reduce disability to a problem of individual functioning resulting from a disease or disorder that requires professional intervention. The unit of analysis is the patient and outcomes are determined by that person's level of functional improvement. In this model, practice patterns and policies tend to be provider-driven and focus on eliminating (to the extent possible) the condition that is causing the physical disability. Rehabilitation nursing practice is guided by this perspective and definition of disability. For example, the Functional Independence Measure (FIM™) (Keith, Granger, Hamilton, & Sherwin, 1987), a tool that is widely used in rehabilitation nursing, is based on this model.

Disability also has been defined from a civil rights and social justice perspective, which is commonly described as the social model of disability. This model identifies disability in society and presumes that it is society's responsibility to change to provide equal opportunities for PWDs. This perspective tends to discount (or even ignore) the problem of the disabling condition at the individual level and focuses on changing society. The unit of analysis in the social model is society, and outcomes are measured by the degree of social equality that is achieved. This perspective assumes that the PWD should be independent and self-determining, that all PWDs have the expertise and desire to have total control over decisions affecting their lives (including healthcare decisions), and that they have a responsibility to be activists to change society. It also assumes that PWDs should accept their disabling condition as part of who they are and that they must embrace the ideals of this perspective.

Both the rehabilitation and social perspectives and the resulting models described in the preceding paragraphs provide

some insight into important attributes of the concept of disability. However, each perspective also imposes assumptions about how PWDs should be. The WHO's attempt to integrate the models is a step forward. However, concern remains that when endorsing and implementing the new model of disability, approaches to research and practice will continue to carry the implicit assumptions of the previous perspectives, in particular the functionalist assumptions.

In addition to being directed by the rehabilitation model of disability, rehabilitation nursing texts and curricula also incorporate conceptual models and theories of nursing practice, such as those proposed by Orem, Roy, Henderson, and King (Derstine & Hargrove, 2001; Secrest, 2000). While these nursing theories and models are patient-focused and help define how to care for PWDs, they are, like the rehabilitation model of disability, either firmly rooted in, or carry undertones of, a functionalist perspective (Fawcett, 1993; Meleis, 1997). While more recent nursing theories, such as those of Parse and Newman (Fawcett, 1993), broaden our definitions of nursing from a functionalist perspective to integrating the perspectives of people and populations, these broader definitions are not yet reflected in our teaching and practice. Therefore, the implicit assumptions of a functionalist perspective often guide both our definitions of disability and our approaches to the care of PWDs.

Services, practice, and research for PWDs designed from either of the perspectives described in this article will continue to be fragmented, incomplete, and inherently too narrowly focused, centering on one perspective while virtually eclipsing the other. For example, services designed solely from a functionalist perspective focus on the physically disabling condition and the resulting effect on functioning, often eclipsing other important aspects of a person's life. Conversely, services designed from the disability rights perspective focus on changing society and promoting self-determination for PWDs, placing them in an often unchosen and unwanted role of care manager, advocate, activist, and expert.

Zola (1989) argues for "real" integration of the two perspectives to form a "universal" approach to disability. He contends that both the social and rehabilitation models tend to segregate PWDs, focusing on their differentness and special needs. He calls for a "universal policy toward disability" (p. 421), in which the uniqueness and interdependence of people in society are recognized by designing a flexible social world for all. However, the fact that PWDs do have special issues and needs cannot be discounted. Research into the unique needs of the PWD is limited, but several authors have identified issues specific to them that include more vulnerable health status, secondary limitations, accelerated aging, complex service needs, problems with insurance, and limited opportunities for gainful employment (Brandt & Pope, 1997; DeJong & Brannon, 1998; DeJong, et al., 2002; Nosek, 1993).

Conclusion

People with disability experience it within the larger context of living their lives. When the disease process or societal barriers are central in our research, policies, and practice, the effect of disability is considered out of the larger context of living a

life. This narrow focus results in programs and policies that often eclipse other important aspects of a person's life.

Rehabilitation nursing can help expand this focus by recognizing that disability is often conceptualized from a provider-defined, functionalist perspective within our practice environments. Recently, rehabilitation nurse researchers have begun to explore how people who are living with disabilities perceive disability and its influence on their lives (Paterson & Stewart, 2002; Pilkington, 1999; Secrest & Thomas, 1999; Treloar, 1999). To enhance our understanding of disability, we must continue to expand research to include the perspectives of people living with disability. Research questions and practice must focus on what is important in their lives, how disability influences their abilities to live their lives, and what policies and services will help them meet their needs. This approach is supported by other rehabilitation researchers (Brown & Heinemann, 1999; Crow, 1996; Marks, 1997; Treloar, 1999).



Gaining a better understanding from PWDs about how they experience disability will continue to provide rehabilitation nursing researchers, policy makers, and practitioners new insights into the dimensions of disability that are most salient, and the strategies that PWDs employ to mediate the effects of their disability on their abilities to live the lives they want to live. This heightened understanding will help to bridge the gaps that have been identified among the perspectives discussed here.

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Disability Defined

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